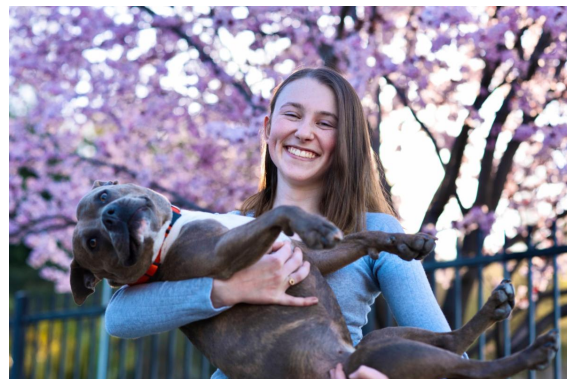

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Meet Ruby – Our New Intern



Hi! I'm Ruby, and I'm a new member of the PXE International team. I am a sophomore at the University of Washington studying Food Systems, Nutrition, and Health with a minor in Data Science. I love dogs (especially pit bulls) and any kind of craft project. I'm really looking forward to our upcoming project that connects my nutritional science focus to PXE.



With Ruby in the lead, we are excited to launch a new project in the coming weeks to consider the connection between nutrition and PXE. And we'd love for you to participate! Anyone who is (1) interested in nutrition, (2) open to switching up their diet a little bit, and (3) willing to fill out a brief survey each week! No prior nutrition understanding is required.

[I'm interested in the Nutrition Study](#)

We will be hosting a webinar on Wednesday, May 25th at 7 PM ET for anyone who is interested in learning more about the project. We will go over the reasoning behind the study as well as any details you need to participate. Feel

free to stop by or watch the recording later if you can't make it to the live meeting.

Nutrition Webinar

[Register Here](#)

PXE at the United Nations

Sharon Terry, president and CEO of PXE International, will speak at the Women's Entrepreneurship Day Celebration on May 20th at the United Nations. This honor is because of her entrepreneurial way of meeting the challenge of PXE and for all of the tools and resources she has created for all advocacy organizations. Of special note is her involvement in [iHope Genetic Health](#), a program of Genetic Alliance. If you would like to watch the day's events, click the button below.

[United Nations Event](#)

May is Mental Health Awareness Month

Your mental health is just as important as your physical health, and PXE International wants to spread that message and fight the negative stigma surrounding seeking aid for mental health.

Similar to regular medical check-ups it is beneficial to receive regular mental health check-ins. Because of the pandemic, there has been a big push for tele-health. Many mental health resources have a telemedicine option, making it more accessible. Just like any "physical" health condition, mental health conditions have their own unique symptoms. But experts know that common ones might include excessive worrying, fear, or sadness, changes in sleeping and eating habits, substance abuse, and thoughts of or actions of self-harm.

If you or a loved one are experiencing mental health symptoms or are interested in learning more, there are numerous resources that can be found online. Some of these include:

[National Alliance on Mental Illness](#)

[National Institute of Mental Health](#)

[CDC: Mental Health](#)

If you are experiencing a mental health crisis, these are current hotlines that you can utilize to receive immediate aid:

- Text "NAMI" to 741741
- Text "HELLO" to 741741
- National Suicide Prevention Lifeline-1-800-273-8255

PXE International cares about you and your mental health too. If you would like to participate in a one-hour simple mindfulness experience, with an emphasis on being gentle with yourself in the midst of stress, sign up with the link below. [Register here.](#)

Genetic Testing Results

Have you undergone genetic testing to determine your ABCC6 mutations? PXE International curates all of the mutations in an online database run by the National Institutes of Health. We'd like to add your results to the rest. We do this without your name or any other identifying information. Then when doctors find mutations in someone, they check the database to see if the mutation is disease-causing.

Contribute your genetic test results to this important database. If you have genetic test results, email them to info@pxe.org. If you would also like to add them to your registry record, we will show you how to do that.

Webinar Highlight

Thank you to everyone who took the time to respond to the Webinar Interest form. We have heard your responses, and while we organize new webinars we would like to highlight some that are already in our library.

Many of you showed interest in current research related to eye manifestations. The 2021 Virtual Conference webinar [PXE and Eye Research](#) will be of interest for you.

If you would like to let us know what webinars interest you, there is still time to tell us by completing the Webinar Interest form below.

Webinar Input

Contact Us

We love to hear from everyone and help in any way we can! Mail us at info@pxe.org. Staff read emails daily. Or call us at **202.362.9599 x208**. If it is outside of office hours, leave a message and we will get back to you as soon as we can.